Hosted by:

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Global Albinism Alliance

Standing Voice

World Forum on Skin Cancer Prevention and Management in Persons with Albinism

Post-Meeting Report

October 2025

Cape Town, South Africa

Executive Summary

Skin cancer is a significantly life-shortening health risk for persons with albinism, especially for those living in the tropics and resource-limited settings. The first World Forum on Skin Cancer Prevention and Management in Persons with Albinism, held in October 2025 in Cape Town, South Africa, aimed to address this challenge. Lead by the International League of Dermatological Societies, Standing Voice and The Global Albinism Alliance, the forum gathered a wide stakeholder community to hear from experts, collaborate as a multi-disciplinary group, and develop coordinated actions to amplify the impact of future interventions to reduce the frequency of skin cancer in this cohort and ensure appropriate services are effectively available to manage skin cancer as it arises. The forum participants included: dermatologists, scientists, global health experts, international health agency representatives, such as the World Health Organization (WHO) and International Agency for Research on Cancer (IARC), pharmacists, advocates, and most importantly those with lived experience to ensure that all considerations and outputs were relevant and patient focused.

A wide appreciation of the disproportionate burden of preventable skin cancer among persons with albinism is crucial to securing the political will to develop appropriate national and international policies that will ensure the embedding of effective services within existing health systems around the world.

Hearing first hand from those with lived experience sharing their realities, as well as from experts and implementers, framed a rich and productive two days of discussions and workshops. The international perspectives facilitated shared understanding and ensured globally appropriate solutions underpinned the conclusions and recommendations reached.

Skin cancer in persons with albinism has been neglected and poorly understood. Presenting an accurate global burden of this issue will enhance efforts to advocate for change.

Effective and successful skin cancer prevention programs are already underway in some areas of the world. Coordinating internationally to bring these together to develop a blueprint program to guide health ministries to progress national action plans for skin cancer prevention and management within their countries is feasible.

Understanding the resources required to implement such programs, compared to the cost of NOT providing them, will assist in identifying the means to move forward with action plans.

Noting the two relevant World Health Assembly Resolutions adopted in 2025: the first recognizing “skin disease as a global public health priority”, and the second considering “rare diseases a global health priority for equity and inclusion”, we now have the political mandate to establish appropriate health as well as social policies and translate these into the provision of suitable services and protections for those affected by albinism to ensure they minimize their risk of life threatening skin cancer.

1. Purpose and Significance of the Forum

The meeting marked the first global forum dedicated specifically to skin cancer prevention and management in persons with albinism (PWA). Convened by international dermatology bodies, NGOs, and albinism-led organisations, its overarching aim was to develop a coordinated global strategy to reduce preventable illness and death from skin cancer among PWA worldwide.

Participants included dermatologists, public health experts, NGOs, policymakers, researchers, and people with lived experience of albinismfrom across 30 countries , reflecting a multi-stakeholder and rights-based approach.

2. Skin Cancer and Albinism as a Global Health and Human Rights Issue

Speakers consistently emphasized that:

- Skin cancer, particularly non melanoma skin cancer, is one of the leading causes of death among persons with albinism globally. This is especially noted in resource limited settings in the tropics occurring at a young age

- Although often considered easily treatable, non-melanoma skin cancers frequently become fatal in PWA due to late diagnosis, lack of access to care, and absence of preventive measures including educational and awareness initiatives

- The burden is global, affecting Africa, Latin America, the Caribbean, Asia, the Pacific Islands, and the Middle East—not Africa alone

Through her opening address, the UN Independent Expert highlighted the lack of disaggregated data, under-representation of PWA in cancer registries, and their exclusion from climate-change adaptation and cancer-prevention policies.

3. Prevention Is Central

A recurring theme was that skin cancer in PWA is largely preventable through:

- Regular access to sunscreen, shade structures and sun-protective clothing including sunglasses and hats
- Early education on UV exposure risks, starting in childhood
- Routine skin screening and early treatment of pre-cancerous lesions

The forum welcomed the recent WHO decision to include sunscreen for persons with albinism on the Essential Medicines List, seen as a major policy breakthrough enabling national-level advocacy.

4. Models of Effective Practice from Around the World

Several countries and regional case studies demonstrated what works in practice:

a. Tanzania and Malawi (Standing Voice Programme and Dermalawi)

- A decentralised dermatology network integrated into public health systems
- Over 300 clinic sites, reaching more than 13,000 persons with albinism
- Emphasis on:
  - Training local clinicians and surgical officers
  - Community advocates for mobilisation and trust-building
  - Integrated data systems for follow-up and risk flagging
- Evidence of improved sun-protection behaviours and reduced advanced disease

b. Côte d'Ivoire – Albivoire (Secours medico-social Ivoirien and Fondation Pierre Fabre programme)Community-based prevention and awareness campaigns

- More than 2800 persons with albinism Integrated in a data system Integration of dermatological, surgical, psychosocial, vision and educational support
- Local sunscreen manufacturing

c. Fiji and the Pacific

- Strong political commitment, including dedicated government budgets
- National albinism registry, free sunscreen provision, and routine clinics
- High-visibility advocacy linked to International Albinism Awareness Day

d. Brazil and Latin America

- Long-standing albinism associations advocating for national public policy (in May 2025, Brazil adopted a national policy to improve protection and health care for people with albinism)
- Ongoing challenges with under-diagnosis and under-reporting, but growing civil-society engagement

e. Africa, Regional and National Action Plans on Albinism (AAN)

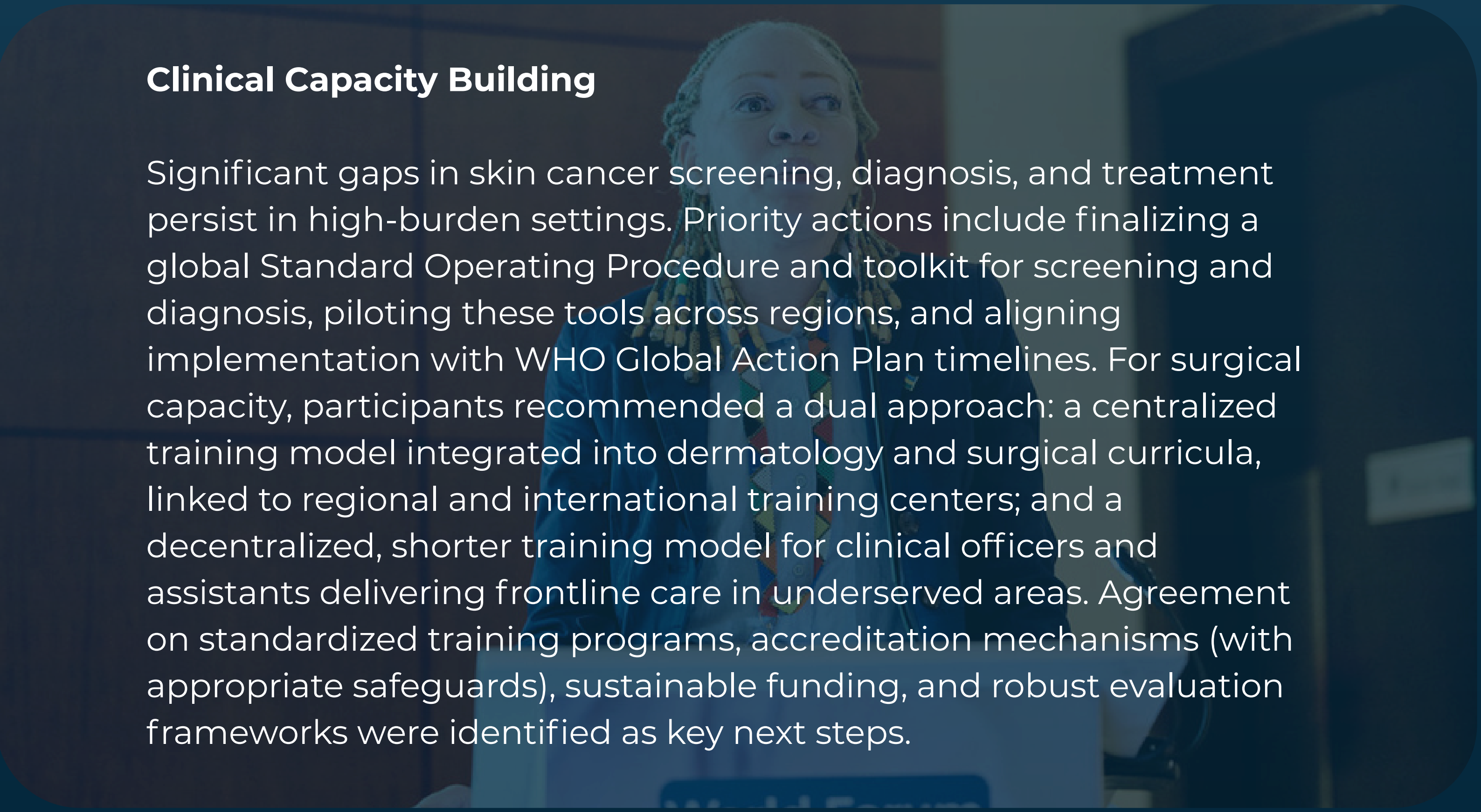
- The African Union Regional Action Plan on Albinism, launched in 2015 and renewed for a further ten years in 2021, has driven the domestication and implementation of national action plans across the continent, with growing coordination between governments, national human rights institutions, and civil society
- Key pillars support health services, particularly the rollout of skin cancer prevention and management initiatives
- Persistent challenges remain, particularly in securing sustained government financing, addressing implementation gaps, and translating policy commitments into tangible, measurable improvements on the ground

5. Technical Workshop Outputs

A series of four technical workshops was convened to inform the development of a Global Action Plan aimed at reducing preventable morbidity and mortality from skin cancer among persons with albinism (PWA), particularly in low-and middle-income countries. The workshops brought together program implementers, clinicians, advocates, and researchers to identify priority actions across service delivery, clinical capacity, access to photoprotection, and advocacy.

Scaling and Coordination of Programs

Participants highlighted that current efforts are fragmented and insufficiently coordinated to achieve scale. Establishing coalitions at global, regional, and national levels was identified as a critical priority to harmonize models of care, reduce duplication, and enable more strategic fundraising through consortium approaches. Strengthening advocacy for inclusive public policies, such as health insurance coverage for PWA, alongside improved data systems was seen as essential. Participants emphasized the need to agree on shared indicators, map geographic “hotspots” of need, and demonstrate the impact of existing programs to strengthen government engagement and investment. Capacity-building for healthcare workers and organizations of persons with albinism was identified as a foundational enabler of sustainable scale.



Clinical Capacity Building

Significant gaps in skin cancer screening, diagnosis, and treatment persist in high-burden settings. Priority actions include finalizing a global Standard Operating Procedure and toolkit for screening and diagnosis, piloting these tools across regions, and aligning implementation with WHO Global Action Plan timelines. For surgical capacity, participants recommended a dual approach: a centralized training model integrated into dermatology and surgical curricula, linked to regional and international training centers; and a decentralized, shorter training model for clinical officers and assistants delivering frontline care in underserved areas. Agreement on standardized training programs, accreditation mechanisms (with appropriate safeguards), sustainable funding, and robust evaluation frameworks were identified as key next steps.

Access to Photoprotection

Photoprotection was recognized as a cornerstone of prevention. Beyond sunscreen, affordable protective clothing, hats, and locally appropriate solutions, such as natural shade in school environments, were emphasized, alongside reasonable educational accommodations for PWA. While sunscreen is now included in the WHO Model List of Essential Medicines for PWA, further guidance is required to support national procurement and quality-assured local production. At country level, tailored strategies involving multiple ministries, not only health —are required. Expected outcomes include inclusion of sunscreen in national essential medicines lists, tax exemptions, clear regulatory frameworks, integration of albinism-related skin cancer risks and appropriate prevention strategies into health training curricula, and systematic education of PWA and their families. Achieving these outcomes will depend on improved data, research, and capacity-building of civil society and healthcare providers.

Advocacy and Communication

Effective policy change will require a combination of targeted government advocacy and public engagement. Core messages include the high and preventable burden of skin cancer among PWA, its impact on children and young people, and the feasibility of addressing it through a limited set of policies. Advocacy should be led by people with lived experience, supported by clinicians, researchers, NGOs, civil society, media, and influential community leaders. Priority actions include compiling best advocacy practices, conducting a comprehensive data and landscape analysis, and launching a multifaceted public awareness campaign to elevate skin cancer prevention and care for PWA within national health agendas.

6. Advocacy, Policy, and Systems Change

Key advocacy priorities identified included:

- Embedding albinism and skin cancer into national cancer control plans as well as into health science curricula
- Consider developing information packages for schools on specific needs of students with albinism, for shade structures, correct position in class, and sitting away from open bright windows to optomise their learning potential
- Aligning action plans with the World Health Assembly resolution on skin diseases
- Explore benefits of categorising skin cancer in PWAs as a neglected tropical disease
- Developing and implementing national and regional action plans on albinism, particularly in Africa through African Union frameworks as well as involving National and Regional Dermatological Societies to assist with implementation strategies
- Ensuring persons with albinism lead and shape policies affecting them

7. Data, Research, and Evidence Gaps

The forum acknowledged critical gaps:

- Absence of reliable, disaggregated epidemiological data from many areas of the world
- Limited research capacity within albinism communities
- Need for partnerships with academic and global health institutions to generate policy-relevant evidence

Participants agreed that better data is essential to demonstrate impact, guide prevention strategies, and influence governments and funders.

8. Key Messages and Shared Commitments

Across sessions, the following consensus emerged:

- No one with albinism should die from a preventable skin cancer
- Prevention and early care are medically more effective, well as more cost-effective than treating advanced disease
- Sustainable progress depends on local capacity, government ownership, and coordinated global action
- The forum should be a starting point, not a one-off event, leading to:
    - A global action plan
    - Peer-reviewed publications
    - Ongoing collaboration and accountability

Overall Conclusion

The meeting framed skin cancer in persons with albinism as a **preventable global health emergency and a human rights issue.** It demonstrated that effective solutions already exist but must be **scaled, coordinated, and embedded into policy and health systems,** with persons with albinism at the centre of decision-making.

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